

## REVIEW

# Key factors in paediatric organ and tissue donation: an overview of literature in a chronological working model

Marion J. Siebelink,<sup>1</sup> Marcel J. I. J. Albers,<sup>2</sup> Petrie F. Roodbol<sup>3</sup> and Harry B. M. van de Wiel<sup>4</sup>

1 University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

2 Department of Pediatrics, Division of Intensive Care, Beatrix Children's Hospital, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

3 Wenckebach Institute for Medical Education, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

4 Department of Health Psychology, Wenckebach Institute for Medical Education, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

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## Correspondence

Marion J Siebelink, Dept of Management Affairs, University Medical Center Groningen LA10, PO Box 30.001, 9700 RB Groningen, The Netherlands. Tel.: +31 50 3619837; fax: +31 50 3614351; e-mail: m.j.siebelink@umcg.nl

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## Summary

There is a growing shortage of size-matched organs and tissues for children. Although examples of substandard care are reported in the literature, there is no overview of the paediatric donation process. The aim of the study is to gain insight into the chain of events, practices and procedures in paediatric donation. Method; a survey of the 1990–2010 literature on paediatric organ and tissue donation and categorization into a coherent chronological working model of key events and procedures. Studies on paediatric donation are rare. Twelve empirical studies were found, without any level I or level II-1 evidence. Seventy-five per cent of the studies describe the situation in the United States. Literature suggests that the identification of potential donors and the way in which parental consent is requested may be substandard. We found no literature discussing best practices. Notwithstanding the importance of looking at donation care as an integrated process, most studies discuss only a few isolated topics or sub-processes. To improve paediatric donation, more research is required on substandard factors and their interactions. A chronological working model, as presented here, starting with the identification of potential donors and ending with aftercare, could serve as a practical tool to optimize paediatric donation.

## Introduction

There is a growing worldwide shortage of organs and tissues for transplantation, especially for children needing size-matched organs and tissues. Over the last 8 years, 283 children in the Eurotransplant countries died while on the waiting list (Eurotransplant International Foundation. Figures on children's organ donation <16 y/o). Other donation and transplantation registries in Europe and the USA report the same need for donor organs [1–3]. Moreover, the number of paediatric donors is decreasing [4]. Although adult living and deceased donation are effective sources for some paediatric transplant programs (e.g. liver, lung), other paediatric programs depend heavily or entirely on paediatric donation (e.g. heart).

In view of the shortage of organs, the paediatric donation process would be expected to have been optimized in terms of process management. This, however, does not seem to be the case. Examples of substandard care include failure to identify potential donors, failure to notify the organ procurement organizations, failure to discuss donation with families and cultural barriers between potential donor families and medical staff [2,5]. Moreover, the American Academy of Pediatrics (AAP) reported that there is no overview or control of the donation process, which is remarkable given the current political and societal focus on health care quality management and the emotional weight of the issue [2,6].

Such a lack of overview could have several causes. Firstly, there could be a lack of pertinent research. Sec-

ondly, there could be a lack of a comprehensive frame of reference, which complicates the integration of available facts, observations and opinions.

To address this lack of insight, we performed an overview of the literature, focusing on key factors (events, processes and procedures) that determine the quality of the paediatric donation process. Subsequently, we ordered the resulting facts, observations and opinions according to their objectives so as to generate a chronological working model that could serve as a frame of reference for the development of best practices.

## Materials and methods

The Embase, Amed, Eric, PsycINFO, Google Scholar and Medline databases were searched using the terms organ don\* or tissue don\* and child, paediatric, pediatric, infant, mourning, grief, parent decision, communication or ethics. Articles from 1990 through June 2010 were included. All terms were in controlled and free text. Subsequently, reference lists of relevant articles were screened for further sources (the snowball method). The levels of evidence were categorized following the USPSTF guidelines [7]. Articles that discussed adult donation or donation by anencephalic patients were excluded.

Data were categorized by their object of study. We identified five phases. Phase 1 is the identification of the potential donor and phase 2 is characterized by the organization of donation at the level of the professional, the team and the hospital. Phase 3 is about communication with the parents. References to parents in our study also include legal guardians. Phase 4 consists of the medical care for the donor. Phase 5 is the care and aftercare for the grieving parents. General reflections on ethical and public aspects regarding organ donation are treated separately.

## Results

A total of 32 relevant articles were found: 16 editorials, case reports, policy statements and reviews, six qualitative studies, six quantitative studies and four case/record studies. None could be classified as Level I or II-1 evidence [7]. Twenty-four studies (75%) describe conditions in North America and eight in European countries.

### Phase 1: Donor identification

A 2006 North American plea for the use of 'organ donation best practices' in children explicitly mentioned failure to identify potential paediatric donors as a barrier to donation and suggested that organ procurement officials should be contacted well before brain death is pronounced [8]. Organ donation best practices should also

include the development of patient-population-specific 'trigger tools' such as a Glasgow Coma Score of 4 or 5 in a brain-injured mechanically ventilated patient [8]. Brierley [9] suggested in a review that paediatricians should be made more aware that children dying in the emergency department are potential tissue donors [9]. In a case study, Kieboom *et al.* [10] used the example of heart valve donation to illustrate the relevance of physicians' awareness of the possibility that small infants could become donors. Several authors have suggested standardized protocols to help physicians recognize infants and very young children as potential donors [8,10,11].

To conclude, the awareness required to develop best practice guidelines in paediatric donation exists, but no such guidelines were found. The role for the intensive care team in signalling donation is underexposed.

### Phase 2: Hospital organization

There is debate in the literature over the conflicts between forensic medicine and donation, the role of the organ procurement organizations (OPOs), the need for protocols, the hospital culture and the education about donation for professionals.

In an editorial Sturmer [11] discussed the conflicting interests of forensic medicine and the legal ramifications of the medico-legal death investigation system on the one hand and donation of organs on the other hand. Sturmer suggested that the classification of potential causes of death and meticulous documentation of injuries by the attending physicians and the medical examiner could help prevent unnecessary loss of potential donors in the USA. In its 2002 and 2010 policy statements, the AAP corroborated Sturmer's views on these issues [2,12].

The AAP's 2010 policy statement recommended the use of local OPOs or hospital staff specifically trained in organ procurement. In a survey of all OPOs in the USA in 2005, Webster and Markham [13] suggested that loss of donors could occur when an eligible donor is not referred for evaluation by the OPO [13]. Several authors opine that an attending, well-informed and sensitive, family oriented staff is required during the full procedure – from identification to procurement [6,14,15]. Vane *et al.* [16] and Rodrigue *et al.* [17] argued that active involvement of the attending professional staff contributes to the number of parents who consent to donation. A retrospective survey ( $n = 78$ ) by Weiss *et al.* [18] corroborated this view. Weiss found parental interactions with hospital personnel during their child's critical illness and death, and the timing of the request for organ donation, extremely influential in many parents' decision-making [18]. Based on a medium-sized record-based study ( $n = 105$ ), Morris *et al.* stated that the contact between medical staff and

parents had a significant impact on donation and recommended open visiting hours to facilitate the discussion of organ donation at a time when staff feel that the families are most receptive [14].

A 2006 policy statement [8] by the American Medical Association (AMA) advocates a culture of hospital accountability (e.g. close monitoring of donation performance). Several authors refer to the donation process in terms of 'total medical management' and emphasize that the quality of the donation process depends heavily on the quality of its procedures and routines, as well as on the quality of the overall coordination process [14,16,19–21]. In a qualitative study ( $n = 24$ ), Macnab *et al.* [21] concluded that a central checklist and process are required to ensure that all relevant aspects of bereavement care are implemented [21]. This was especially valid in hospitals with a level I trauma programme, where paediatric donors were more likely to be found [13]. In a qualitative study of bereaved families, Macnab *et al.* found that support provided by the nursing staff was rated as excellent [21].

From an organizational perspective, specific attention is required for donation after circulatory death (DCD). In a qualitative study of professionals ( $n = 88$ ) Curley *et al.* [22] emphasized the importance of each individual hospital's culture through the role she designated the hospital's mission and core values. She also pinpointed relevant controversies surrounding DCD, and the need to develop a conceptual framework for a DCD programme. Studies by Curley *et al.* and Joffe *et al.* stated that paediatric staff voiced many concerns, but would be willing to adopt a DCD protocol to fulfil a family's wishes [22,23]. Kolovos *et al.* [24] suggested DCD is an option in select circumstances to serve grieving families who wish to donate and to increase organ availability for transplantation [24]. DCD enables recovery of two of the most needed organs for children, the kidneys and the liver [2]. In a study of paediatric critical care nurses ( $n = 93$ ), Mathur *et al.* [25] identified a deficit of knowledge of DCD and suggested that educational intervention can improve knowledge, confidence and comfort concerning the DCD process [25]. With regard to educational donation programmes in general, the AAP [2] stated that attending physicians should have training in dealing with the death of a child, 'including confidentiality and religious, cultural and ethical issues.' Oliver *et al.* [26] noted the value of the formal education of health care personnel which also includes brain death and organ donation [26].

To conclude, some authors promote bringing in OPOs, whereas others emphasize the importance of attending physicians and nurses. Some authors state that there is a lack of knowledge, but we did not find remarks on existing educational programmes for professionals.

### Phase 3: Communication with the parents

Ten studies discuss communication between health care professionals and parents. Given the distinct themes these studies focused on, we subdivided them as follows:

- 1 Breaking bad news.
- 2 Discussing donation.
- 3 Decisions about donation.

#### *Breaking bad news*

The first step is delivering parents the bad news about their child's condition. With respect to organ donation, it is important that the parents fully understand the term 'brain dead'. Based on a qualitative study of bereaved parents ( $n = 77$ ), Oliver *et al.* [26] concluded that support and explanation are prerequisites to enable parents to arrive at sound decisions. Oliver *et al.* suggest that parents should be allowed to witness brain death tests and the results should be discussed with them [26]. Parents need time to process and accept the bad news [15,27]. Delay in the initiation of brain death protocols allows family members time to deal with the initial shock and begin to concentrate on the grieving process [16]. In a record-based study ( $n = 33$ ), Vane *et al.* [16] concluded that allowing time did not only positively affect the parents' emotional status, but also their willingness to consent to donation [16]. The death notification should be decoupled from the organ consent process to increase the rate of family consent [2].

#### *Discussing donation*

The second step is actually discussing donation. Brierley [9] suggested that 'failing to provide parents of a brain dead child with accurate information or the opportunity to donate their child's organs' is unfair [9]. The AAP stated that organ donation is an integral part of end-of-life care that provides families with a final decision concerning a loved one [2]. The AAP further suggested that staff could start communication with the family of a critically injured child while in the emergency room, to avoid rushing later [2]. In general, parents are not prepared to cope with this decision [15,27,28]. Some authors therefore recommend providing additional emotional support when mentioning donation. Oliver *et al.* [26] and Morris *et al.* [14] suggest that the number of refusals decreases when the donation question is asked compassionately by a physician with whom the family feels comfortable [14,26]. Rodrigue *et al.* [17] showed that if a family member or a member of the health care team raises the possibility first, donation is significantly more likely than when it is mentioned by an organ procurement official [17]. When DCD is considered, it should be discussed only after the decision to withdraw support or terminate

care has been established, unless parents take the initiative [2].

#### *Decision about donation*

The third critical moment is making the decision to donate. Oliver *et al.* [26] point out that the decision is determined by how parents feel about donation at the time. Rodrigue *et al.* [17] also stated in a recent survey of bereaved parents ( $n = 74$ ) that donation attitudes and knowledge were positively associated with the decision to donate [17]. Oliver *et al.* [26] stated that it takes time for the parents to reframe the decision about donation as giving meaning to their child's meaningless death. Some parents regret their decision to refuse donation as having been made too quickly because of lack of time [26]. Once the death is accepted, it is possible for parents to consider the benefits of donation. This can lead to better decision-making [16].

In general, the parental decision is aided by the presence of a person the family knows and trusts and who understands donation [6]. Bellali and Papadatou [6] stated that 'significant others' can influence the parents' final decision. These significant others can be family members, relatives and friends, but also members of the ICU personnel or a trusted family physician [6]. When an attending physician was actively involved, the willingness to donate was found to increase [16]. Several studies [14,16,28] described the difference in donation willingness between the relatives of a deceased adult and those of a deceased child. According to Morris *et al.* [14] parents of young children are more likely to agree to donation. A psychological explanation for this phenomenon is that these – in that instance Northern American – parents could be identifying with other parents whose child's life is at stake [14].

In conclusion, the importance of professional empathy and a well-trusted team was often mentioned. It appears important to separate the steps of the communication process. Good communication influences donation willingness positively.

#### **Phase 4: Medical care for the donor**

The AAP stressed the importance of the accurate determination of neurological death and the need for additional observation or testing if any doubts remain [2]. Both timely determination of neurological death and aggressive medical management of the potential donor should limit the number of medical failures with procured organs [2]. In a single-centre retrospective study of 199 children who fulfilled the criteria for brain death, organs were not procured in 22% of cases after consent had been granted, primarily because of cardiocirculatory failure, underscoring

the need to aggressively support cardiovascular function and maintain organ perfusion [15]. Care for the donor is 'the natural extension of care for a critically ill or injured patient' [20].

To conclude, little attention was paid in the literature to the medical treatment of paediatric donors.

#### **Phase 5: Aftercare**

According to Bellali and Papadatou, [19] further research is required about the impact of donation on parental grief. Kieboom *et al.* [10] described how fulfilling the specific wishes of the parents about care and aftercare can help realize donation [10]. Macnab *et al.* [21] pointed out that good professional care also includes aftercare and evaluation for parents, and stated that follow-up contact from the hospital about 4 weeks after death is valued [21].

In a retrospective descriptive study, Mazor [29] suggested further research to elucidate the psychological needs of families of DCD donors and to generate best practice guidelines for paediatric DCD [29].

Both OPO's and nurses, clergy, paediatricians, family physicians, child-life specialists and social workers should support the family during the donation process and should provide long-term follow-up. According to the AAP, the success of these efforts is an integral part of increasing organ donation within the local community [2].

To conclude, little is known about best practices regarding aftercare to the next of kin and the effects of the donation procedure on the direct circle of acquaintances of the family.

#### **General perspective**

Seventeen studies included reflections on ethical and public issues.

Ethical considerations or opinions can be classified along the four classic principles: beneficence, non-maleficence, autonomy and justice [30]. The first two principles should be applied to the possible donor and could require careful coaching of distressed parents of a dying child. A new ethical debate has started on heart donation in children after DCD. DCD may even offer an opportunity to reduce waiting time and waiting list mortality in children whose survival depends on heart transplantation [31]. In a special section, Zinner [32] discussed the relevant ethical principles regarding living sibling-sibling organ donation and paediatric consent [32]. She assumed that parents are often the best decision-makers, but that children also have autonomy, as she stated that adolescents of 13 or 14-years-old are able to make their own decisions

[32]. Morris *et al.* [14] argued that both parents should agree to donation, which can be seen as a form of family autonomy. Again from an autonomy perspective, Walker *et al.* [27] and Morris *et al.* [14] argued that withholding the donation option from parents constitutes an infringement on their autonomy.

The public domain deals with legal issues, governmental responsibility and family discussions about donation. Donation is subject to health care legislation. The United Nations Convention on the Rights of the Child, for instance, states that children have the right to be informed about public health issues. Children also have the right to be informed about organ and tissue donation [33].

Closely connected to legal issues is the responsibility of the government with regard to donation. There is clearly a strong public interest in increasing the availability of organs and tissues [17]. The role of the government should be to correct people's false assumptions, to provide clear information to the general public and to schools and to educate children about donation [6,34–36]. The AAP states that institutions that care for children need to increase awareness of the need for organs with the same enthusiasm with which blood donation and immunization programmes are promoted through public campaigns [2]. Rodrigue *et al.* [17] showed that parents who consented were more exposed to information about donation in the 6 months prior to their decision [17].

In an editorial, Sheldon [36] stressed the importance of parents being aware of their children's attitudes towards organ donation. Weiss *et al.* [18] mentioned that parental consent could be increased by encouraging parents to discuss organ donation with their children. In action research conducted with students ( $n = 336$ ) Waldrop *et al.* [37] stated that family members should be encouraged to discuss their feelings about donation in a non-crisis situation. Thinking and talking about death and donation, especially when related to children, generates anxiety and discomfort. However, it is important to normalize family discussions about end-of-life choices [37].

## Discussion

The literature search we performed revealed that paediatric donation has not been charted adequately. Original data are sparse and fragmented: current practice seems to be based on sometimes contradictory expert opinions. We identified a limited number of studies on key factors. Many articles were policy papers, editorials and commentaries, and most originated in North America. We found little material describing the situation in Western Europe. Our findings stress the gap between current knowledge of paediatric donation and current practice in Europe.

Given the sparse data, it is clear that no empirically proven substandard factors could be identified. However, there are some indications that the identification and the preparation of potential donors and the way parental consent is sought could be regarded as substandard. Although there is consensus on seeing donation care as a chain of interdependent processes and events, most studies discuss only a few, relatively isolated topics. Few authors describe a broader context of paediatric organ and tissue donation, and even fewer stress the importance of the total process management [2,15,17]. Some findings are worth mentioning. The role of the paediatric nurse in this donation process is underexposed. Our own experience suggests that PICU nurses play a significant role in donor identification and care and in the communication with and care for the parents. It is not clear from the literature as to who is best suited to raise the question of donation: a local organ procurement organization, hospital staff specifically trained in organ procurement [2] or a member of the health care team [17]. The literature emphasizes the importance of well-educated professionals, but we did not find any specific remarks regarding educational programmes. Only Mathur *et al.* [25] suggested educational interventions for DCD [25]. It should be noted here that donation after brain death remains the gold standard for organs; DCD is still controversial and should be considered only if the paediatric donor is unlikely to satisfy brain death criteria. Many articles paid attention to the communication process, but little attention was paid to aftercare. The medical treatment of a paediatric donor is also underexposed. Overall, the interaction between the phases seems to be of relevance.

Despite this fragmented or scattered picture of events, processes and procedures, it was possible to order key factors in a chronological guideline or checklist. Although empirical proof is lacking, a number of recommendations and conclusions could be distilled from the literature. Without striving for completeness and following our own chronological model, some questions need to be asked.

*Identification of donor:* can we improve the number of children who are identified as potential donors and would it be helpful if knowledge about paediatric donation was included in the paediatrics curriculum? Active steps that could be taken also include the development of online paediatric donation guidelines.

*Hospital organization:* what are the factors (circumstances, processes, involved persons, considerations etc.) that affect the quality of the parents' donation decision, and what are the factors that influence the attitude of the professional staff?

*Communication:* who should discuss donation with the parents – the compassionate physician with whom the

family feels comfortable or a specialized professional OPO?

*Medical care for the donor:* can specific guidelines and well-informed professionals contribute to donor management in paediatrics, and therefore decrease the number of medical failures?

*Aftercare:* which factors affect the quality of life and, in particular, the mourning process of parents who consent or refuse donation and which type of professional support should be made available?

*General perspective:* public campaigns about donation should also include children. How can family members be encouraged to discuss donation in a noncrisis situation? What are the rights of children to make their own decisions about becoming donors?

Answers to these questions will improve paediatric donation and, subsequently, paediatric transplantation.

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